

**REPORT OF THE KENTUCKY  
ACQUIRED BRAIN INJURY  
PLANNING PROJECT  
OCTOBER 2000**



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Pamela Westermeyer, advocate  
Kathy Williams, Department for Vocational Rehabilitation  
Jenny Wurzbach, Cardinal Hill Rehabilitation Center

We are also indebted to Robert Walker, of the University of Kentucky, for his invaluable assistance in conducting two focus group meetings and for his assistance with data analysis and interpretation.

*Note: Reference is made throughout this report to traumatic brain injuries and acquired brain injuries. A traumatic brain injury is commonly understood to be an injury to the brain resulting from a blow to the head. The term acquired brain injury refers to an injury to the brain that may result from a variety of factors, including a blow to the head, a lack of oxygen, exposure to toxic substances, allergic reactions, or similar events. The focus of planning project efforts was on needs of people with acquired brain injuries, which includes a larger group of people than the more narrowly defined traumatic brain injury group.*

## Purpose of the Acquired Brain Injury Planning Project

The planning project was funded in part by a grant from the U.S. Department of Health and Human Services, Bureau of Maternal and Child Health. Funding was also received from the Kentucky Traumatic Brain Injury Trust Fund. The Brain Injury Services Unit, in the Department for Mental Health and Mental Retardation Services, Kentucky Cabinet for Health Services, administered the project. The project was conducted for a one year period beginning August 1, 1999 and ending July 31, 2000.

Planning project efforts were focused on answering the following questions for Kentucky:

1. What is the estimated incidence of acquired brain injuries?
2. What is the estimated prevalence of people with acquired brain injuries receiving services in existing service delivery systems?
3. What are the service needs of people with acquired brain injuries?
4. What public resources are available to meet the service needs of people with acquired brain injuries?
5. What are the gaps in services for people with acquired brain injuries?

Information to answer these questions was gathered from the following sources:

1. A review of initial data from the brain injury surveillance pilot project funded by the Traumatic Brain Injury Trust Fund
2. A screening of individuals receiving services from community mental health centers, state operated institutions serving people with mental illness, substance abuse programs, and programs for people with mental retardation and developmental disabilities
3. A written survey of people with acquired brain injuries throughout the state
4. Two focus groups including professionals in the field of acquired brain injury, people with acquired brain injuries, service providers, family members, and advocates
5. Five focus groups including people with acquired brain injuries and their family members or advocates
6. Interviews with state agency staff who administer publicly funded programs
7. A review of written information and regulations governing publicly funded programs

Planning Project assessment efforts were restricted to determining which services and supports people with acquired brain injuries need to remain in their natural homes and communities, and the resources available to meet those needs. Kentucky is in the early stages of its development of community based supports and services to this population and the information collected during this project will be used to further this effort.

The information collected during this planning period has been summarized in this report. It has served as the foundation of Kentucky's Action Plan for the further refinement and development of services to people with acquired brain injuries. The Action Plan is included in this report.

Information about available resources has been summarized in a Resource Guide, intended for use by case managers working with children and adults with acquired brain injuries. A copy of the Resource Guide, and additional copies of this report, may be obtained by contacting:

Brain Injury Services Unit  
100 Fair Oaks Lane, 4W-C  
Frankfort, Kentucky 40621  
Phone: 502-564-3615  
Fax: 502-564-9010  
E-mail: [brain.injury@mail.state.ky.us](mailto:brain.injury@mail.state.ky.us)

## The Estimated Incidence of Acquired Brain Injuries in Kentucky

The Centers for Disease Control and Prevention (CDC) has determined that traumatic brain injury occurs annually at a rate of 95 per 100,000 in the United States population. According to data reported by the CDC, 78% of those who sustain a brain injury are expected to survive.

Using the CDC's incidence rates, an estimated 3,763 people may have suffered a traumatic brain injury in Kentucky in 1999. Of those, an estimated 2,935 people might be expected to survive the injury. However, these estimates do not include people who have sustained an acquired brain injury by anoxia (loss of oxygen to the brain), allergic reactions, toxic substances, or other medical clinical incidents resulting in impaired cognitive abilities or impaired physical functioning (i.e. meningitis, encephalitis, tumors, etc.). These numbers, therefore, should be considered to be underestimates of the number of persons with brain injuries in the commonwealth during that time period.

To better estimate the incidence of traumatic and acquired brain injuries among Kentucky's citizens, the Traumatic Brain Injury Trust Fund Board of Directors approved funding in 1999 for the completion of a pilot surveillance project, as required by KRS 211.474. The Kentucky Injury Prevention and Research Center conducted this pilot surveillance project. Three data sets from 1997 (the most recently available data), including the NCHS Kentucky supplemental Death file; the Kentucky Hospital Discharge Data; and trauma data from the University of Kentucky, University of Louisville, and Kosair Children's Hospital trauma registries were analyzed. The purpose of the analysis was to answer several questions, including:

- How many Kentuckians sustained fatal or serious (hospitalization required) traumatic brain injuries or acquired brain injuries in 1997?

Table 1 details the number of fatal and non-fatal cases of both traumatic and acquired brain injuries (excluding cases of brain injury that occurred secondary to coronary problems) found among these three data sets for 1997. These figures should also be considered an underestimate of the numbers of people in Kentucky who have sustained brain injuries because pilot surveillance project data were not collected from all border states where Kentuckians may have received hospital care for brain injuries.

Similarly, these data do not allow a determination to be made regarding the number of people who survive with long-term disabilities as the result of acquired brain injuries, or the severity of those disabilities. However, because it is known that even the most mild brain injury can result in a life-long need for support, it is not unreasonable to regard all people who survive a brain injury as being potentially in need of services.

Table 1: The number of non-fatal and fatal cases of traumatic and acquired brain injuries in 1997, using selected hospital data.

| Type of Injury         | Total Number | Number Surviving | Number of Fatalities |
|------------------------|--------------|------------------|----------------------|
| Traumatic Brain Injury | 3160         | 2359             | 801                  |
| Acquired Brain Injury  | 1925         | 1036             | 889                  |
| Total                  | 5085         | 3395             | 1690                 |

**Summary.** Conservative estimates of the number of people with brain injuries suggest that 3,395 Kentuckians acquired brain injuries in 1997 and that an additional 2,935 people may have received a traumatic brain injury in 1999. The 1999 estimates do not include persons who may have sustained brain injuries as a result of an event other than a blow to the head. Additional mechanisms are needed that would allow for more accurate estimates of the number of people who will require continued support and assistance due to brain injuries. Toward this end, the Board of Directors of the Traumatic Brain Injury Trust Fund has approved continued funding of the surveillance project.

\*\*\* A copy of the complete report of the pilot surveillance project may be obtained from:

Brain Injury Services Unit  
100 Fair Oaks Lane, 4W-C  
Frankfort, Kentucky 40621  
Phone: 502-564-3615  
Fax: 502-564-9010  
E-mail: [brain.injury@mail.state.ky.us](mailto:brain.injury@mail.state.ky.us)

The Traumatic Brain Injury Trust Fund Board of Directors has approved continued funding of this surveillance project. The Kentucky Injury Prevention and Research Center will continue to compile information about the incidence of acquired brain injuries in the Commonwealth using data from the databases noted above from 1998. The second report is expected to be available by July 1, 2001.

## Estimated Prevalence of People with Acquired Brain Injuries in Existing Programs

An acquired brain injury often results in permanent changes to a person's ability to maintain employment, interpersonal relationships, and independent living. Additionally, the person may experience personality changes, sleep disturbance, mood disturbances, impaired concentration and memory, or health problems. Consequently, the person or the family may seek assistance and support to cope with these long-term effects of the injury.

Until the implementation of the Acquired Brain Injury Medicaid Waiver Program in 1999, and the Traumatic Brain Injury Trust Fund Program in 2000, few community based programs designed specifically for people with acquired brain injuries have existed in Kentucky. Given this lack of brain injury-specific services, individuals and their families are likely to have sought care from other programs throughout the state. These include programs for people with mental retardation and developmental disabilities, mental illness, and substance abuse, in addition to vocational training programs.

**Methods.** State-funded programs may be regarded as the "safety net" for persons with disabilities, when private funding is unavailable or when private providers are unable to meet an individual's needs. Planning project staff attempted to identify the extent of brain injury among individuals receiving care in state funded mental health, mental retardation/developmental disabilities, substance abuse, and vocational training programs. This study was also undertaken to learn about services most likely to be used by persons with brain injuries. This information can be used to assist in identifying training needs of staff, in addition to increasing the understanding of the impact of acquired brain injuries on various service delivery systems. The methods used included:

1. Support Coordinators and Case Managers employed in Mental Retardation/Developmental Disabilities programs operated by each of the state's fourteen (14) community mental health centers were asked to review their current case loads and review records to determine the number of people they serve who have acquired brain injuries. A written definition of acquired brain injury was provided to each case manager, with a telephone number to call if he or she had any questions regarding the process or the definition. Thirteen centers responded to this request.
2. Each state-operated ICF/MR facility was asked to count the number of people with acquired brain injuries currently residing in the facility. Information was gathered from social work staff and from record review. Two facilities responded to this request.
3. Three state-funded hospitals for the mentally ill responded to a request to count the number of people with acquired brain injuries currently admitted to the facility at the time of inquiry. Information was gathered from social workers and by asking persons admitted on that day whether they had ever had a brain injury.

4. The Department of Vocational Rehabilitation (DVR) was asked to count the number of people with acquired brain injuries who were engaged in vocational training programs in FY 1999. Information was gathered from the DVR's data base. The DVR does routinely record whether individuals seeking assistance have a brain injury and staff were able to provide this information by querying its data base.
5. State funded outpatient mental health and substance abuse programs in thirty seven (37) randomly selected counties across the state were asked to screen every consumer receiving services on a given day for acquired brain injuries. A screening tool was provided to these programs for this purpose. A copy of the screening tool may be found in Appendix I. The methodology of the screening effort is described below.

**Method of random screening effort.** Approximately 20% of outpatient mental health, substance abuse, and therapeutic rehabilitation programs were randomly selected from a listing of all sites in the state. One residential program serving persons with substance abuse problems was also included in the survey. The executive directors of the centers were mailed a letter describing the aims and methods of the special study and they were asked to assist by communicating the plan to mid-level managerial and direct supervisory staff. About one month later the instrument was mailed to the selected sites with brief instructions on how to complete the instrument. The letter included the specified dates in March 2000 for the data collection. All programs were to conduct the surveys on one of the specified dates.

An instrument was designed based on findings in the literature of typical features associated with brain injury and mild brain injury in particular. The instrument included some demographic items such as age and gender. It also included items specific to the type of head injury such as automobile accident, bike accidents, work related injuries, being knocked out in a fight or having a drug overdose resulting in unconsciousness. It included the age at which the injury occurred and sequelae to thinking, physiology, or mood following the injury. It included items on the number of times a coma was experienced and the total hours of coma.

**Results.** Table 2 indicates the estimated number of people with brain injuries served in those programs responding to inquiries from planning project staff. These estimates should be interpreted cautiously, however. Because the funding sources accessed by persons who have brain injuries do not usually require organizations to report the number of people with brain injuries they serve, that information has not been systematically or routinely collected. Training of mental health, mental retardation/developmental disabilities, and substance abuse treatment professionals does not typically include information about the assessment, rehabilitation, and service needs of persons with brain injury. Consequently, they may not routinely screen their clients for brain injuries.

Additionally, to access existing services, a person with a brain injury may need to have another qualifying diagnosis. The qualifying diagnosis would then become the primary diagnosis entered into the person's record, rather than the diagnosis of an acquired brain injury. For example, a person suffering from depression resulting from a brain injury may seek services from a community mental health center. The community

mental health center staff may be likely to list the person's diagnosis as "depression", without further reference to the brain injury. Similarly, a child who suffers cognitive and other functional impairments due to a brain injury may be diagnosed as "mentally retarded" or "developmentally disabled" without further reference to the brain injury. Reliance upon existing data sets and clinical records, therefore, may not yield an exact count of the number of people with acquired brain injuries currently receiving services.

Similarly, the instrument used in the random screening of community mental health and substance abuse programs was not validated (there is no validated brain injury history instrument) and inferences about the degree of actual damage resulting from the reported injuries cannot be made. Since there was no control over which consumers were assessed on the selected day, these data cannot be generalized to all mental health consumers in the state.

Table 2: Estimated number of people with acquired brain injuries served in programs responding to the inquiry.

| <b>Organization or Program Responding to Inquiry</b>               | <b>Estimated Number of People with Brain Injuries Served</b> | <b>Estimated Percentage of Total Population Served by Organization or Program</b> |
|--------------------------------------------------------------------|--------------------------------------------------------------|-----------------------------------------------------------------------------------|
| Regional MR/DD Programs (Community Mental Health Centers)          | 107                                                          | <1%                                                                               |
| State operated ICF's/MR                                            | 33                                                           | 14%                                                                               |
| State operated hospitals for people with mental illness            | 52                                                           | 13%                                                                               |
| State operated Nursing Facilities                                  | 15                                                           | 6%                                                                                |
| Department of Vocational Rehabilitation                            | 598                                                          | 2%                                                                                |
| Randomly selected community mental health/ substance abuse program | 557                                                          | 44% of all persons screened                                                       |

The available data do support the notion that persons with brain injuries seek assistance from providers of services designed to meet the needs of individuals with a variety of disabilities. These preliminary data also suggest that there is every reason to be concerned about the number of persons with brain injury among mental health and substance abuse programs. The question of whether these individuals are seeking services because of co-occurring conditions or because of the sequelae of brain injury deserves further investigation. So, too, does the question of whether these individuals are receiving appropriate and effective services.

The emphasis on the provision of services for people with brain injuries is fairly recent in Kentucky. The lack of focus on brain injuries in the education and training of many human service professionals, brain injury may be a condition about which providers in the state-supported system of care may be largely uninformed. These data suggest a need to prepare service providers to work with this population.

**Summary.** These findings should be interpreted cautiously, given the absence of any requirement that service providers routinely screen recipients for brain injuries or record such information in individual records and the limitations of the screening instrument. The available information suggests that people with brain injuries are now served in programs designed to serve individuals with mental health needs, mental retardation/developmental disabilities, and substance abuse problems. The need to prepare service providers to work with people with brain injuries is noted, as is the need to further investigate the appropriateness and effectiveness of services offered to people with brain injuries.

## Service Needs of People with Acquired Brain Injuries

The service needs of children and adults with acquired brain injuries in Kentucky were identified through the use of a written survey and by conducting a series of focus groups across the state. Detailed below are the results of these efforts.

### **I. Survey of the Needs of People with Brain Injuries**

A two page written instrument was developed to survey people with acquired brain injuries and their families. The survey was piloted with a group of volunteers who had brain injuries. As a result of their input, the survey instrument was revised twice. A copy of the final survey instrument and enclosures may be found in Appendix II.

Because no centralized database exists, it was necessary to enlist the cooperation of organizations known to provide services to people with acquired brain injuries. These organizations included schools, inpatient and outpatient rehabilitation facilities, state-operated facilities, and one out of state facility serving children from Kentucky. A list of organizations contributing to this effort may be found in Appendix III.

Each organization was asked to count the number of people with acquired brain injuries utilizing its services within the past two years. The Department of Vocational Rehabilitation counted the number of people served within the past five years. The number of people identified was then forwarded to planning project staff. Planning project staff then forwarded postage paid envelopes to be addressed by and mailed from that organization. Each envelope contained a cover letter explaining the project, a survey, notice of the planned focus group meetings and an addressed, postage paid envelope in which to return the survey.

A total of 3,500 surveys was forwarded to cooperating organizations and distributed to people with acquired brain injuries throughout the state. However, because people may have accessed services from multiple organizations, it is probable that many people received multiple copies of the survey. To guard against the possibility that people would return more than one survey, the cover letter specifically directed the recipient to return only one. A total of 714 surveys were returned and 638 were usable. Because it was not possible to determine the number of unduplicated survey recipients, it was not possible to determine the rate of return. Survey results were summarized using simple percentages of the total number of respondents.

### **II. Characteristics of Survey Respondents**

**Gender of respondents.** Survey respondents were 39% female and 59% male. The remaining 2% of the respondents did not indicate their gender. The CDC estimates that men are injured twice as often as females. The survey sample includes more women than expected, given the CDC's figures.

**Current living arrangements.** Table 4 details the current living arrangements of survey respondents. Eighty percent (80%) of all survey respondents reported living with family members. This suggests that the responsibility for caring for an individual with a brain injury is most likely to rest with the family, rather than with paid caregivers.

Table 3: Current living arrangements of survey respondents.

| Current Living Arrangement | Percentage of Respondents |
|----------------------------|---------------------------|
| Alone                      | 18%                       |
| With Parents               | 39%                       |
| With Spouse                | 31%                       |
| With Children              | 5%                        |
| With Other Family Members  | 5%                        |
| With Roommate              | 3%                        |
| In Nursing Home            | 8%                        |
| In Group Home              | 2%                        |
| Other                      | <1%                       |

**Ages of respondents.** Respondents were grouped according to the ages commonly used to determine eligibility for publicly funded services. Persons who receive a brain injury prior to age 22 years may be eligible for services for persons with mental retardation/developmental disabilities. Persons aged 21 years to 65 years may be eligible for adult services, including the Acquired Brain Injury Medicaid Waiver Program. Persons aged 60 years and older may be eligible for services for the aged. The majority of survey respondents fell between the ages of 20 years and 50 years of age. Table 4 compares the age groupings of respondents at the time of the survey and at the time of injury.

Table 4: Percentage of respondents in various age groups at the time of survey and at the time of injury.

| Age                      | Under 22 years | 21 years to 65 years | Over 60 years |
|--------------------------|----------------|----------------------|---------------|
| <b>At time of survey</b> | <b>11%</b>     | <b>71%</b>           | <b>10%</b>    |
| <b>At time of injury</b> | <b>44%</b>     | <b>47%</b>           | <b>8%</b>     |

**Age at time of injury.** Forty four percent (44%) of the respondents reported being injured prior to age 22 years, thus it would be expected that a similar proportion of persons in this age group would respond to the survey. However, comparisons of current ages and ages at time of injury reveal that persons currently under the age of 22 years are under represented in the survey sample.

A comparatively high proportion (43%) of all respondents indicated that they acquired a brain injury before the age of 22 years, during the developmental period. These people may be eligible for services from programs serving people with mental retardation and developmental disabilities. This may add to the already overwhelming number of persons seeking assistance from such programs.

The proportion of respondents injured during the developmental period is also of interest because efforts to identify the number of persons receiving services in

programs designed to serve people with mental retardation/developmental disabilities found fewer than 1% among the population served by Regional Mental Health and Mental Retardation Board programs (see page 9 for details). This suggests that the diagnoses for children who receive brain injuries may not be reflective of these injuries and raises the questions of whether the services they subsequently receive are appropriate to their needs.

It is unlikely that the failure to identify persons with brain injuries among the population of individuals with mental retardation/developmental disabilities currently enrolled in programs occurs because they have no service needs. A high proportion of all survey respondents indicated that their service needs are not now being met, as noted in Section III.

It is of particular interest that 27% of all respondents indicated they were injured as teenagers. This suggests that efforts may be needed to educate teens about the prevention of brain injuries.

**Length of time since injury.** Table 5 details the length of time since respondents were injured. Twenty one percent (21%) of all respondents noted that their injuries occurred more than ten years ago, suggesting that some people with brain injuries may need additional supports and services for extended periods.

**Employment status of respondents.** Only 24% of respondents indicated that they were employed. The most frequently cited reasons for not working included: can't do any job (23%); retired due to age or disability (17%); can't do a previous job (11%); and can't find work (11%). These data support the notion that having a brain injury may serve as a significant impediment to employment.

Table 5: Length of time since the brain injury was acquired.

| Length of Time Since Injury | Percentage of Respondents |
|-----------------------------|---------------------------|
| Over 30 years               | 2%                        |
| Over 20 years               | 5%                        |
| Over 10 years               | 14%                       |
| Within the past 10 years    | 76%                       |
| Within the past year        | 15%                       |

**Insurance coverage.** Eighty four percent (84%) of the survey respondents indicated that they have medical coverage. Table 6 details the types of insurance or government programs used by respondents. Respondents could select more than one option, so the total does not equal 100%. The greatest burden for payment of needed services clearly falls upon the Medicaid and Medicare programs, with 61% of all respondents reporting use of these resources.

**Summary.** The survey sample consisted of more men than women, which is consistent with national statistics indicating that males are more likely to receive brain injuries than females. However, the sample included more women than expected, given the CDC's estimates of the proportion of men and women who receive traumatic brain injuries. Children appear to be under-represented in the sample.

Table 6: Insurance coverage of survey respondents

| Type of Insurance          | Percentage of Respondents |
|----------------------------|---------------------------|
| Worker's Compensation      | 4%                        |
| KCHIP                      | 1%                        |
| Private                    | 37%                       |
| Medicaid                   | 29%                       |
| Medicare                   | 32%                       |
| Both Medicaid and Medicare | 9%                        |
| Other                      | 1%                        |

Eighty percent (80%) of all respondents reported they were living with family members, suggesting that families, rather than paid caregivers, are most likely to assume the responsibility for caring for people with brain injuries.

A significant proportion of survey respondents were injured as teenagers, indicating a need to focus on prevention with this group. Similarly, many respondents report that they were injured prior to age 22 years, suggesting that they may be eligible for services in an already overburdened mental retardation/developmental disabilities service system.

Twenty one percent (21%) of all respondents indicated that their injuries occurred more than ten years ago, suggesting that some people with brain injuries may need services and supports for extended periods.

Few respondents were employed at the time of the survey. Reasons given for unemployment lend support to the suggestion that having a brain injury presents a significant impediment to employment.

Most survey respondents (84%) reported that they have medical coverage. The greatest burden for payment of needed services rests with Medicaid and Medicare, however, with 61% of the respondents indicating use of at least one of these resources.

### III. Needed Services Identified by Survey Respondents

Survey respondents were asked to indicate their preferences for future living arrangements, and their service needs in the following categories: getting services or equipment; learning new skills or receiving therapy; daily living; school/job; visiting with others; and legal assistance. Respondents were asked to indicate whether they were currently receiving the needed services. Additionally, they were asked to identify the reasons why they were not receiving needed services. Overall, survey respondents most frequently indicated the need for case management, psychological services, and cognitive rehabilitation, as detailed below.

Ninety percent (90%) of all respondents indicated their preference for a future living arrangement. Table 7 details the preferred future living arrangements of survey respondents. Of those persons who responded to the question, the overwhelming majority indicated a preference to live in their own homes or with their families. This is notable because 98% of all respondents report that they are now living alone or with family members and these findings strongly indicate a preference to continue to do so.

This suggests that efforts to develop services for people with brain injuries should focus on supporting individuals and families in their efforts to remain at home.

Table 7: Preferred future living arrangements of survey respondents.

| Living Arrangement                                                        | Percentage of Respondents |
|---------------------------------------------------------------------------|---------------------------|
| Live in my own home or with family, independently or with occasional help | 94%                       |
| Live in a supervised home in the community                                | 5%                        |
| Live in a nursing home                                                    | 1%                        |

**Getting services or equipment.** Case management services are encompassed in this survey category. Forty two percent (42%) of all respondents indicated a need for assistance in obtaining services and 21% noted that they need assistance coordinating the services they do receive. Twenty three percent (23%) of respondents noted a need for equipment such as a wheelchair or computer. An additional 17% of respondents specified a need for personal care or attendant services. Twenty seven percent (27%) of all respondents stated a need for help with their health.

**Psychological or mental health services.** Table 8 details the psychological or mental health services needed by survey respondents. Services in this survey category include interpersonal, marriage, or grief counseling; treatment of mood disorders or mental illness; treatment for substance abuse or chemical dependency issues; and interventions to increase appropriate social behavior.

Psychological and mental health services and cognitive rehabilitation services were among the most frequently selected items that respondents indicated they needed. This data appears to validate the finding that a large proportion of consumers screened in community mental health and substance abuse programs reported a history of brain injuries, as discussed in Section II.

Few respondents (6%) indicated the need for help to control alcohol or drug use. This is surprising since one study suggests that up to 42% of people with traumatic brain injuries reported heavy use of alcohol prior to their injuries. The CDC estimates that 50% of persons who receive a traumatic brain injury are intoxicated at the time of the injury. It is believed that this survey finding may be the result of a poorly worded question. The prevalence of substance abuse problems among persons with acquired brain injuries in Kentucky deserves further investigation.

Table 8: Psychological and mental health services needed by survey respondents

| Need Psychological or Mental Health Service | Percentage of Respondents |
|---------------------------------------------|---------------------------|
| Help with behavior                          | 33%                       |
| Help to improve mood                        | 44%                       |
| Help to feel better about myself            | 42%                       |
| Help managing stress & things that upset me | 45%                       |
| Help learning to be around other people     | 21%                       |
| Help to control alcohol and/or drug use     | 6%                        |
| Grief counseling                            | 6%                        |

Also included in this category are services that may be referred to as cognitive rehabilitation. Sixty two percent (62%) of the respondents stated that they had a need for services to help improve their memory, while 44% noted a need for help to solve problems.

**Other therapies.** Respondents indicated a need for other therapies including physical therapy, occupational therapy, and speech/language therapy, as follows: 28% specified a need for help learning to walk, lift, or balance themselves; 14% stated a need for help learning to eat, dress, take a bath, or go to the bathroom by themselves; and 9% indicated a need for help learning to talk or to communicate in some way to others.

**Daily living.** This survey category addresses the need for assistance with housing, child care, transportation, housekeeping, money management, and respite for caregivers. Table 9 details the responses received in this category. The biggest need for services in this category was transportation.

Table 9: Needed assistance of survey respondents in daily living

| Needed Assistance with Daily Living                           | Percentage of Respondents |
|---------------------------------------------------------------|---------------------------|
| Help with transportation                                      | 31%                       |
| Help managing my money                                        | 23%                       |
| Help finding a place to live that I can afford                | 18%                       |
| Someone to come stay with me so my caregiver can have a break | 18%                       |
| Help learning to do housekeeping, cooking, & shopping         | 13%                       |
| Help taking care of my children                               | 5%                        |

**School/job.** Twenty six percent (26%) of all survey respondents indicated that they would like to return to school. While 11% noted they would like to do better at their jobs, 31% stated that they would like to find a job. Given the low rate of employment among respondents, this finding would seem to highlight the need for employment assistance.

**Visiting with others.** This category of services included opportunities to socialize with others. Twenty one percent (21%) of all survey respondents indicated that they would like to go to church. Thirty two percent (32%) indicated that they would

like to meet with other people who have brain injuries, suggesting the need for support groups for people with acquired brain injuries. Finally, 28% stated that they would like to find places to go to be with other people.

**Legal.** Sixteen percent (16%) of all survey respondents indicated a need for help with legal problems. The nature of the legal problems that respondents experienced was not surveyed.

**Reasons for not receiving services.** Only 24% of all survey respondents indicated that they were currently receiving needed services. Table 10 details the reasons noted for not receiving needed services. Recipients could select more than one reason, therefore totals do not equal 100%.

Table 10: Reasons for not receiving needed services.

| Reason Not Receiving Services        | Percentage of Respondents |
|--------------------------------------|---------------------------|
| Do not know what services would help | 39%                       |
| Can't afford or insurance won't pay  | 28%                       |
| Do not have transportation           | 17%                       |
| Services not available in area       | 16%                       |
| Cannot do the paperwork              | 14%                       |
| Cannot find a person to help         | 12%                       |

The number of survey respondents who indicated that they do not know what services would help suggests the need for increased patient education about common outcomes of brain injuries and the kinds of interventions that are available to address or improve the individual's functioning. Additionally, it may suggest the need for people with brain injuries to maintain ties with social workers or case managers who can direct them to appropriate resources when they are ready to seek them. This might also be achieved by the provision of a readily accessible information and referral hot line.

The counties of survey respondents who indicated that services were not available in their areas were identified for the purpose of determining which areas of the state might benefit from further development of services for individuals with brain injuries. Interestingly, it was determined that some services were indeed offered in these counties.

This finding certainly deserves further exploration. It suggests that people with brain injuries may be unaware of existing resources, but this cannot be concluded with any degree of certainty given the available information. Other potential reasons for the unavailability of services include: the difficulty agencies statewide are now experiencing in hiring and retaining direct service staff; waiting lists for services; the appropriateness of existing services for people with brain injuries; or lack of transportation.

**Summary.** The services most frequently reported to be needed by respondents were case management, psychological and mental health services, and cognitive rehabilitation services. Given the proportion of individuals reporting a history of brain injuries among the mental health programs screened, the need too prepare mental health providers is again highlighted.

Surprisingly, few respondents reported a need for help to control alcohol or drug use. The current literature suggests that drug and alcohol use may be problematic among persons with brain injuries. This suggests a need to further explore the prevalence of substance abuse problems among persons with brain injuries in Kentucky.

An overwhelming majority of respondents indicated a preference to remain in their own homes or with their families in the future. This suggests that an emphasis on strengthening the capacity of families to support their loved ones at home would be appropriate.

The need for assistance with transportation was noted by nearly one third of all survey respondents. Survey results also suggest that support groups for persons with brain injuries would be welcomed.

Only 24% of all respondents reported that their needs are currently being met. A need for patient education about the outcomes of brain injuries and available services was suggested. Further exploration of the reasons for the reported unavailability of services in counties where services currently exist is warranted.

#### IV. Needed Services and Desired Outcomes Identified by Focus Group Members

Seven focus groups were held across the commonwealth for the purpose of generating input from consumers and professionals regarding what services and supports people with brain injuries need to live in the community. The design, question, and findings of the focus groups are detailed below.

##### Focus Groups for Professionals and Persons with Brain Injuries.

Two of the focus groups were designed to include a large proportion of professionals, in addition to persons with brain injuries and their families. Robert Walker, who is a member of the Traumatic Brain Injury Trust Fund Board of Directors, facilitated both of these focus groups. In reporting the results of these focus groups, minor changes to the language used by the groups were made for the purpose of clarifying the information for readers who may not have been present at the meetings.

**Procedures for Advisory Committee focus group.** The first focus group was composed of 21 members of the planning project Advisory Committee and staff of the Brain Injury Services Unit. It occurred at the February 25, 2000 meeting of that body, held in Elizabethtown. Eleven participants were professionals, one participant was a professional who had a brain injury, one participant was a professional whose son had a brain injury, and six participants were family members or individuals with brain injuries.

A nominal group process was used to elicit ideas from the group. This approach assures every member an equal opportunity to offer ideas and suggestions. It does not allow for discussion until the menu of ideas has been fully formed. When using this process, members offer ideas one at a time until the group feels it has identified all ideas. The group then assigns priority to the ideas by voting their degree of importance. This creates a clear ranking of ideas ranging from most important to least important. However, no idea is left out of the process unless the group, by consensus, decides to omit it.

**Questions asked.** The following questions were posed to the Advisory Committee focus group:

- If we were to picture a comprehensive and ideal community-based brain injury program, what would it look like?
- What services do families need in order to support members with brain injuries who live with them?

**Service domains considered.** The group elected to explore these questions by considering five potential service domains. These included:

- Education
- Transportation
- Living environments
- Leisure and day activities
- Employment

**Top priority items for inclusion in an ideal system of care.** Table 11 details the group's identification of the ten most important elements of an ideal system of care, identified by the group. Table 12 details the top ten most important services for supporting families in the community identified by the group.

**Discussion.** Overall, the results indicate a concern for the development of residential and day programs, and the provision of key information to families. Of special interest was the availability of information about benefits and financial planning for family members. The group emphasized the need for long term supports, especially for life long case management.

**Procedures for Brain Injury Summit Focus groups.** The second focus group was composed of Brain Injury Summit conference participants. The conference was held in Louisville in March 30 and 31, 2000 and was attended by 160 professionals, providers, and persons with brain injuries. Fifteen persons with brain injuries or their family members attended the conference. The conference participants were considered key informants who had unique perspectives on brain injury based on personal as well as professional experience.

Conference participants were asked to select one of four breakout groups, each of which had an assigned topic area. The topics included:

- Family Support
- Leisure and Day Activities and Transportation
- Living Environments
- Employment and Education

TABLE 11: Ten most important elements of an ideal system of care for persons with brain injuries, identified by Advisory Group members.

| # VOTES | IDEAL SYSTEM OF CARE ELEMENT                                                                                     |
|---------|------------------------------------------------------------------------------------------------------------------|
| 13      | Full continuum of living environments in the same facility or on a campus                                        |
| 13      | Long term employment supports                                                                                    |
| 11      | Full continuum of residential settings in the community                                                          |
| 10      | Respite care                                                                                                     |
| 10      | Work training centers like the Carl D. Perkins Center across the state                                           |
| 9       | Training on work behaviors and related social skills                                                             |
| 9       | Sheltered employment with some opportunities for interaction with the public are available on the campus setting |
| 9       | In-home supports services are available                                                                          |
| 8       | A continuum of living arrangements is available from secure to less restrictive settings                         |
| 8       | Age appropriate and brain-injury specific day programs are available                                             |

TABLE 12: Ten most important services needed to support families caring for members with brain injuries, identified by Advisory Group members.

| # VOTES | SERVICE NEED                                                                                                                           |
|---------|----------------------------------------------------------------------------------------------------------------------------------------|
| 14      | Respite care                                                                                                                           |
| 12      | Benefits counselors are available to assist persons with brain injury and their family members                                         |
| 11      | Life long case management is accessible and available to the person with brain injury                                                  |
| 10      | There are stress management and wellness services for family members                                                                   |
| 9       | Families have mechanisms to help them plan for the future financial security of brain injured person after the death of the caregivers |
| 7       | Alternative living solutions are available                                                                                             |
| 7       | Families have access to legal and financial counseling                                                                                 |
| 7       | Families have access to a 24 hour crisis support system                                                                                |
| 7       | Families receive training and education about brain injury                                                                             |
| 6       | Families have access to psychological services paid for by insurers without restrictive limits                                         |

Each group was supplied with the ideas from the February 25, 2000 meeting of the planning project Advisory Group. This was done to provide a starting point for discussion, revision, and addition of ideas about community supports for persons with brain injury and their family members.

Each group used a modified nominal group process, making changes and additions to the existing items and adding new items that had not been suggested by the Advisory Group in February. After ideas had been amended and new items added, the group then assigned priority by voting on the importance of each idea. Those ideas that received the greatest number of votes were ranked highest. All groups then reconvened and reported their results to the assembled conference participants.

**Results of Brain Injury Summit focus groups.** Tables 13 through 18 summarize the five most important components from each topic area identified by the group focusing on that topic.

Table 13: Five most important components of leisure and day program activities identified by Brain Injury Summit focus group.

| # Votes | Components of Leisure and Day Activities                                                                                           |
|---------|------------------------------------------------------------------------------------------------------------------------------------|
| 48      | Well trained staff provide balanced, therapeutic leisure activities in a safe, accessible environment                              |
| 43      | Day Programs that support social skills and that are age-appropriate and appropriate for persons with brain injuries are available |
| 34      | A statewide resource guide is available on the Web and in hard copy on a quarterly basis                                           |
| 19      | Expanded programs to integrate persons with ABI into the post-secondary education system                                           |
| 19      | Providers are educated to offer a variety and greater number of activities to persons with brain injury                            |

Table 14: Five most important components of transportation services identified by Brain Injury Summit focus group.

| #Votes | Transportation Service                                                                                 |
|--------|--------------------------------------------------------------------------------------------------------|
| 56     | Transportation is accessible, affordable, and it accommodates individual needs in all geographic areas |
| 26     | Special ID cards indicating the nature of impairments are issued to persons with brain injuries        |
| 13     | Greater access to and training on adaptive equipment for driving                                       |
| 9      | Retraining on driving skills is accessible to persons with brain injury                                |
| 7      | Public safety officers routinely receive sensitivity training about brain injury                       |

Table 15: Five most important components of family support services identified by Brain Injury Summit focus groups.

| # Votes | Family Support Services                                                                                                 |
|---------|-------------------------------------------------------------------------------------------------------------------------|
| 32      | Respite care to facilitate living at home with families                                                                 |
| 29      | Financial assistance for medication, rent, food, legal representation, etc.                                             |
| 27      | Comprehensive financial counseling regarding Medicaid access, medications, and legal issues                             |
| 24      | Comprehensive legal counseling regarding guardianship, advance directives, criminal justice system, and law enforcement |
| 19      | Temporary housing for family members during the injured person's hospital stay                                          |

Table 16: Five most important components of living environments identified by Brain Injury Summit focus groups.

| # Votes | Living Environment Component                                                                                                 |
|---------|------------------------------------------------------------------------------------------------------------------------------|
| 74      | Full continuum of living environments in the same facility or on 4-6 campuses across the state                               |
| 48      | Smaller group homes and residential settings near to families, with supervision available in every other county in the state |
| 44      | Individualized living opportunities based on the person's level of need and sensitive to changes in level of need over time  |
| 20      | Staff of all residential programs are well-trained in brain injury                                                           |
| 19      | 24 hour care in the natural home setting                                                                                     |
| 19      | Training, counseling, and consultation is available for family members                                                       |

Table 17: Five most important components of employment services identified by Brain Injury Summit focus groups.

| # Vote | Components of Employment Services                                                                                         |
|--------|---------------------------------------------------------------------------------------------------------------------------|
| 51     | More work training centers like the Carl D. Perkins Center across the state                                               |
| 35     | Job coaches help make accommodations in the work place, resulting in increased sensitivity to persons with brain injuries |
| 32     | Neuropsychological evaluations are used in employment placement and training                                              |
| 21     | Benefits are not lost when earning a salary                                                                               |
| 18     | Training in work behaviors and social skills is available                                                                 |

Table 18: Five most important components of employment services identified by Brain Injury Summit focus groups

| # Vote | Components of Educational Services                                                                                                              |
|--------|-------------------------------------------------------------------------------------------------------------------------------------------------|
| 28     | Educators in Kentucky should have required training in ABI issues                                                                               |
| 26     | Children with learning or behavioral problems are assessed brain injury professionals to determine history and evidence of brain injury         |
| 23     | Awareness training for teachers is available about brain injury as an alternative to too frequent use of classes for the behaviorally disturbed |
| 21     | Coordination of brain injury services in Kentucky education                                                                                     |
| 16     | Information is widely distributed about specialized education services for individuals with brain injury under age 21                           |

**Discussion.** The Brain Injury Summit focus groups appeared to emphasize the need to train professionals and the public, and to make information about services and resources more readily available. It should be noted here that the group's interpretation of accessible transportation that accommodates the individual is quite specific. In addition to being handicapped accessible, the group emphasized the need for transportation that is available on-demand and that can be used for leisure purposes, in addition to medical purposes.

In keeping with the information from the Advisory Group focus group, participants at the Brain Injury Summit identified the need for financial assistance, financial and legal counseling, and a full continuum of residential supports for people with brain injuries and their families. The Brain Injury Summit focus groups also echoed the suggestion that vocational training facilities similar to the Carl D. Perkins Center and residential campuses be established throughout the state for persons with brain injuries.

The suggestion from these focus groups that residential campuses be established is in direct conflict with information gathered from persons with brain injuries and their families who responded to the written survey described above. The overwhelming majority (94%) of all survey respondents noted a preference to live in their own homes or with family members in the future.

One possible explanation for this disparity may be the difference in the composition of the focus groups and the survey sample. These two focus groups included a large proportion of professionals, while the survey sample consisted exclusively of persons with brain injuries or their family members. The perspective of each group may differ significantly. However, this disparity is not readily understood from the available data and deserves further exploration.

### Focus Groups Designed for Persons with Brain Injuries and Their Families

Five focus groups were designed primarily for persons with brain injuries and their family members. Carolyn Wheeler, a private consultant, was hired to facilitate each group. A subcommittee of the planning project Advisory Committee and staff met with Ms. Wheeler in January 2000, to determine the format, locations and questions, which would be asked at each focus group meeting.

**Locations and composition of focus groups.** In conjunction with the locations of the five area Councils of the Brain Injury Association of Kentucky, the dates and locations of groups were established. Each focus group gathering was held on a Saturday from 12:30 p.m. to 3:30 p.m. Accessible locations where refreshments could be served were identified.

Table 19 details the location, date and attendance of each group. Although professionals were not encouraged to attend these focus groups, those who came were welcomed. Seven of the 100 total focus group participants were professionals, rather than persons with brain injuries or their families.

Table 19: Location, date, and size of each focus group.

| Location      | Facility               | Date           | Group Size                     |
|---------------|------------------------|----------------|--------------------------------|
| Bowling Green | Holiday Inn Hotel      | April 13, 2000 | 12 people                      |
| Lexington     | Cardinal Hill Hospital | April 20, 2000 | 25 people<br>(1 professional)  |
| Paducah       | Lourdes Hospital       | May 13, 2000   | 18 people<br>(2 professionals) |
| Louisville    | Radisson Hotel         | May 20, 2000   | 37 people                      |
| Thelma        | Carl D. Perkins Center | June 3, 2000   | 8 people<br>(4 professionals)  |

**Public notice of focus groups.** Information about the focus groups was included with the written survey of the service needs of people with brain injuries described in the previous section. Additionally, radio announcements ran in each locale one week prior to the focus group. News releases concerning each focus group were also distributed to print media in advance of each event. All public notices included a statement that financial assistance was available to defer travel expenses for persons wishing to attend the meetings.

**Questions asked.** The following questions were formulated to be asked at each of the sessions:

- What services would make your life better?
- What service do you want to happen first?
- What services have you received that were most helpful?

- How would your life be different (what would the outcomes be) if the ideal system of publicly funded services and supports were available?

**Format of the focus group gatherings.** At each gathering, the following format provided both an opportunity for participants to learn from one another as well as share information about their needs and concerns:

- Staff of the Brain Injury Services Unit welcomed participants and explained the purpose of the afternoon
- Carolyn Wheeler, Facilitator, asked people to spend ten to twenty minutes talking with others about their experiences with brain injury
- Individuals then introduced themselves to the group
- Each group generated answers to the first question and wrote them on 5 x 8 cards. Cards were then read aloud, categorized, and pinned on a large “storyboard”
- Participants were next given seven adhesive dots and asked to vote for their top three categories by placing dots on the cards in those categories most important to them
- Participants were given a break and then reconvened at their tables.
- For the last question, participants were asked to record their answers, one per 5 x 8 card, as a group
- Each card was subsequently read, categorized, and pinned to the storyboard
- Participants were then given four adhesive dots and asked to indicate their priority outcomes by placing dots on those items most important to them
- Staff of the Brain Injury Services Unit ended the event by explaining the services available through the Brain Injury Services Medicaid Waiver and the Brain Injury Trust Fund

**Needed services and desired outcomes prioritized.** Focus groups varied in their identification of needed services and desired outcomes. Two summary tables follow with the top ranked services/supports and outcomes indicated by location of the group. Table 20 summarizes the top three priorities for needed services identified by each focus group. Table 21 summarizes the top four priorities of desired outcomes for each focus group.

Table 20: Top three priorities for needed services identified by each focus group.

| <b>Priority</b> | <b>Bowling Green</b> | <b>Lexington</b>                     | <b>Louisville</b>                  | <b>Paducah</b>                   | <b>Thelma</b>                       |
|-----------------|----------------------|--------------------------------------|------------------------------------|----------------------------------|-------------------------------------|
| <b>#1</b>       | In home Supports     | Employment Assistance                | Residential Supports (group homes) | Educational Help                 | Support Groups                      |
| <b>#2</b>       | Therapies            | Increasing Independent Living Skills | Employment Assistance              | Financial Help with Medical Care | Public Education About Brain Injury |
| <b>#3</b>       | Social Activities    | Residential Supports (group homes)   | Legal Help/ Estate Planning        | Case Management                  | Case Management                     |

Table 21: Top three priorities for desired outcomes of publicly funded services identified by focus groups.

| Priority # | Desired Outcome                                         | # of Focus Groups Indicating as Priority |
|------------|---------------------------------------------------------|------------------------------------------|
| #1         | • Financial burden of care is lessened                  | 3                                        |
|            | • Positive self-esteem for individual                   | 2                                        |
| #2         | • Peace of mind for family                              | 3                                        |
|            | • Positive self-esteem for individual                   | 1                                        |
|            | • Resources available for higher education              | 1                                        |
| #3         | • Employed & self-sufficient                            | 2                                        |
|            | • Better family relationships                           | 2                                        |
|            | • Positive self-esteem for individual with brain injury | 1                                        |

**Common themes.** While the purpose of these focus groups was to gather information relevant to the aforementioned questions, it should be noted that a great deal more occurred, which was tangential to the stated tasks. During the discussions, several themes emerged which were common to all groups. These may be summarized as follows:

- People who experience a brain injury want a real life, preferably the one they had before they were injured
- Family members want their lives back and to have peace of mind
- Information, at the right time and place, is paramount throughout the experience
- Support groups are needed for emotional support for both the person with the brain injury and family members
- Families with school age children have different issues than families whose children are adults, especially with the school system
- Public education and awareness of the effects of brain injury are needed for all sectors of the community, including family members and professionals who work in human services
- Financial stressors compound the challenges of coping with a brain injury and create hardship
- The challenges posed by persons with brain injuries who have substance abuse problems, and often criminal justice issues, are complex, difficult, and not being addressed by the current system of care
- Emotional consequences and the need for counseling and healing are often life-long in nature

**Discussion.** Common themes that emerged from these five focus groups reflected some of the concerns articulated by the Advisory Group and Brain Injury Summit participants, described earlier in this section. These concerns included the need for life long services, the need for information, the need to relieve financial stress, and the need for public education about the effects of brain injuries.

Priorities for needed services differed widely among focus groups. Substance abuse arose as a concern in this series of focus groups, although services to deal with this problem were not seen as a high priority. This is consistent with the findings of the written needs survey, in which only 6% of all respondents indicated a need for help to control alcohol or drug use.

The following services were most frequently identified as one of the top three priorities for services by participants: case management; employment assistance; and residential supports. This is consistent with the information gathered from the Advisory Group and Brain Injury Summit focus groups. The finding that case management services are needed is also consistent with the results of the written needs survey. Also, the need for support groups identified by these focus groups was also highlighted by the written needs survey.

The residential supports identified by this series of focus groups reflects a request for group home services, rather than the residential campuses referred to by the Advisory Group and Brain Injury Summit participants. As discussed above, this identification of residential supports as a primary need is in conflict with data collected from the written survey. However, it should be noted that 5% of all survey respondents indicated a preference to live in a supervised home in the community in the future. These data collectively suggest that a small group of people with brain injuries may have a significant need for structured residential settings.

Lessening of the financial burden of caring for a loved one and peace of mind were listed most frequently as the top two most important outcomes of publicly funded services. It was also clear from the discussions that ensued during each focus group that both families and individuals with brain injuries would like to reclaim the lives they had prior to the injury.

Complete copies of the reports of the focus groups conducted by Robert Walker and Carolyn Wheeler may be obtained from:

Brain Injury Services Unit  
100 Fair Oaks Lane, 4W-C  
Frankfort, Kentucky 40621  
Phone: 502-564-3615  
Fax: 502-564-9010  
E-mail: [brain.injury@mail.state.ky.us](mailto:brain.injury@mail.state.ky.us)

## Resources Available to Persons with Acquired Brain Injuries In Kentucky

To determine the resources available to individuals with brain injuries in Kentucky, the planning project compiled information from a variety of publicly funded programs. Lists of agencies that provide services and supports for people with disabilities in Kentucky were compiled. An interview format was used and interviews were conducted with key informants in selected publicly funded programs. Information was obtained about eligibility requirements, service definitions, waiting lists, and contact information. A listing of persons interviewed may be found in Appendix IV. The following questions were asked during the interview:

- What services does your program provide and/or financially support that may benefit persons with brain injury?
- How is each of these services defined?
- What are the eligibility criteria for each of the services (including target population)?
- Who is excluded from services?
- What are the average lengths of stay and maximum benefits?
- What is the estimated length of time prior to accessing services?
- What is the estimated number of persons on a waiting list?
- What are the circumstances for moving a person up to the front of the waiting list?
- What is the statewide availability of services in Kentucky? (Number of providers statewide)
- What are the discharge criteria?
- What would a family member (of an individual with brain injury seeking services under your program) need to know in order to access services in the most efficient manner?
- Any additional comments?

It was not the intent of the resource assessment to determine all the available facilities and providers that might be helpful to people with acquired brain injuries and their families. The purpose was, rather, to determine the scope of publicly funded programs that may be accessed by these individuals. Educational resources were not included in this effort, because laws are in place governing special education in the public schools to ensure that all children with disabilities are offered a free, appropriate education. The scope of this resource assessment was limited to the identification of publicly funded resources, programs, and supports available to help people with brain injuries remain in their own homes and communities.

A Resource Guide intended for use by case managers was developed as a result of the resource assessment. It provides detailed information about services offered, program eligibility criteria, service definitions, application processes, and contact information. A complete copy of this resource guide may be obtained by contacting:

Brain Injury Services Unit  
100 Fair Oaks Lane, 4W-C  
Frankfort, Kentucky 40621  
Phone: 502-564-3615  
Fax: 502-564-9010  
E-mail: [brain.injury@mail.state.ky.us](mailto:brain.injury@mail.state.ky.us)

**Results.** The grid on page 33 summarizes the services offered by a variety of programs that may be accessed by persons with brain injuries. Please note that the abbreviations used on the grid are explained on the following page. Eligibility criteria for each program may be found in Appendix V.

**Other Flexible Funding.** The following programs offer flexible funding support and may be utilized for individualized, wrap-around services that are needed to help people with disabilities, establish and maintain community-based living in the least restrictive manner. There are certain restrictions and eligibility requirements for these programs. These funding sources may be accessed only if other programs do not pay for the services requested.

- **Traumatic Brain Injury Trust Fund Benefit Program** - This program offers assistance to persons with brain injuries to help meet the costs of community-based services and supports (see grid). It may also be used to purchase other individualized supports. Per legislation governing the Trust Fund, it may not be used to pay for institutionalization, hospitalization, and medications.
- **Early Periodic Screening Diagnostic and Treatment Special Services** - Early Periodic Screening Diagnostic and Treatment Special Services are other health care, diagnostic services, preventive services, rehabilitative services, treatment or other measures described in 42 USC Section 1396d(a), that are not otherwise covered under the Kentucky Medicaid Program and are medically necessary to correct or ameliorate defects and mental and physical illnesses and conditions.
- **Interagency Mobilization for Progress in Adolescent and Children's Treatment (IMPACT)** - IMPACT helps create and coordinate services that allow a child with an emotional disability to receive care at home or in the community. IMPACT coordinates services between Kentucky's five child-serving systems: education, health, social services, mental health, and the courts
- **Supported Living Program** - Supported Living means providing people with disabilities the individualized help they need to live successfully in a home of their choice. The types of services and benefits funded by the Supported Living Council include home modifications, personal care attendant, respite, help with home purchase or upkeep, skill development, transportation, automotive modification, therapy, and assistive technology.

## Abbreviations

**ABI** - Acquired Brain Injury Medicaid Waiver Program  
**AMH** - Adult Mental Health  
**BIAK** - Brain Injury Association of Kentucky  
**Blind** - Department for the Blind  
**CSHCN** - Commission for Children with Special Health Care Needs  
**CMH** - Children's Mental Health  
**CPC** - Carl D. Perkins Comprehensive Rehabilitation Center  
**EPSDT** - Early Periodic Screening, Diagnosis and Treatment Special Services  
**1<sup>st</sup> Steps** - First Steps  
**H&C** - Home and Community-based Waiver Program  
**Home** - Homecare Program  
**IMP** - Interagency Mobilization for Progress in Adolescent and Children's Treatment  
**IMP+** - IMPACT Plus Program  
**KATSN** - Kentucky Assistive Technology Services Network  
**KCHIP** - Kentucky Children's Health Insurance Program  
**MADD** - Mothers Against Drunk Driving  
**PCA** - Personal Care Attendant Program  
**SA** - Substance Abuse Program  
**SupLiv** - Supported Living Program  
**SCL** - Supports for Community Living Program  
**TBI** - Traumatic Brain Injury Trust Fund  
**VocReh** - Department of Vocational Rehabilitation

**Programs designed specifically for persons with brain injuries.** Three community-based programs and one advocacy group for persons with brain injuries are now available in Kentucky. The programs are the brain injury unit at the Carl D. Perkins Center (vocational training facility), the Acquired Brain Injury (ABI) Medicaid Waiver program, and the Traumatic Brain Injury (TBI) Trust Fund program. The Brain Injury Association of Kentucky provides advocacy and information for persons with brain injuries in the commonwealth.

While these programs now provide a variety of valuable services to people with brain injuries, they may not meet the need for long-term support identified during the needs assessment portion of the planning project. Barriers to the provision of long-term supports through these programs are:

- The ABI Waiver program is designed by to provide intensive rehabilitation services intended to help people with brain injuries re-enter the community. It is not intended to be a source of life-long supports.
- To maintain eligibility for the ABI Waiver program, the individual must continue to show progress. Those persons who do not progress, but who continue to need supports, must be referred to other programs for those supports (most often, the Home and Community Based Waiver).

- The existing ABI Waiver program provider network is small due to restrictive provider eligibility qualifications. There are currently no providers of residential or supported employment services. (Cabinet for Health Services staff are in the process of amending this waiver to resolve this issue at the time of this writing).
- The ABI Waiver program will serve a maximum of 110 people by the end of the third year of implementation. It serves only adults.
- The TBI Trust Fund has benefit limitations of \$15,000 annually and \$60,000 per lifetime. The Trust Fund is intended to fill gaps in services for individuals, rather than to provide extensive support.
- During the second year of its implementation, the TBI Trust Fund program will support five case managers with expertise in brain injury statewide. By the end of the second year, eight case managers will be available statewide. The limited availability of case managers may restrict access to the Trust Fund program and other resources.

**Other programs available to persons with brain injuries.** Nineteen programs serving persons with disabilities were identified, which may also be available to people with acquired brain injuries. However, eligibility for these programs is contingent upon the individual having a diagnosis that will qualify him or her for services. In practical terms, this means that the individual must have a primary diagnosis other than brain injury.

These programs are designed to provide services specific to their populations of interest. Persons with brain injuries often do demonstrate problems similar to those of persons with other disabilities. Because the cause of their problem differs however, it may be necessary to adapt clinical interventions to accommodate their unique needs and specific disabilities.

The training programs for many professionals do not include information about the causes, long-term effects, and emotional impact of brain injuries. Professionals asked to adapt their strategies for persons with brain injuries may be unprepared to do so as a consequence. Information gathered from the focus groups suggests that professionals may need further training to effectively work with persons with brain injuries.

Some programs serving persons with disabilities have waiting lists for services - most notably the Supports for Community Living program, which has a waiting list of more than 1,600 people at the time of this writing. Similarly, the Supported Living program, which accepts applications for assistance in April each year, typically has committed all its funds by May.

It should be noted here, however, that a wide variety of services for children with disabilities exists in Kentucky. This includes a continuum of residential services for children who have qualifying diagnoses. For those persons with brain injuries who continue to need residential services after the age of 21 years, however, the options are severely limited. Only the Supports for Community Living program and the Acquired Brain Injury Medicaid Waiver program offer residential supports to this group. Problems accessing these programs are noted above.

**Gaps in services.** The following gaps in services for persons with brain injuries were noted:

- There is a need for long-term case management. While the TBI Trust Fund offers this, the limited number of case managers available statewide may present a barrier for many people with brain injuries.
- Long-term residential services are currently unavailable to adults with brain injuries, except for those persons who were injured prior to age 22 years, who qualify for the Supports for Community Living Program. This program has an extensive waiting list.
- Prevention efforts and public education about brain injuries appear to be minimal. This is especially troubling in light of the fact that the only known cure for a brain injury is prevention.
- Information about the effects of brain injuries and the services and supports available to assist people and their families may not be readily accessible.

## Summary and Conclusions

Detailed below are the conclusions resulting from the data gathered during the Acquired Brain Injury Planning Project. Data were gathered from the pilot surveillance project funded by the Traumatic Brain Injury Trust Fund, efforts to count or estimate the numbers of people with brain injuries receiving services from state-operated or state-funded programs, and a comprehensive assessment of the needs of persons with brain injuries in Kentucky.

The needs assessment process included a written survey of people with brain injuries throughout the commonwealth, with 638 surveys returned. Additionally seven focus groups were convened to gather input from professionals, family members, and people with brain injuries regarding needed services. Two of the focus groups included a large proportion of professionals and service providers. It is estimated that 180 persons participated in these two groups. Five of the focus groups were designed for persons with brain injuries and their families, and input was received from 100 participants.

Information about the publicly funded services available to persons with brain injuries and other disabilities was collected from 23 programs and was summarized in a resource guide intended for use by case managers. Gaps in services for persons with brain injuries in Kentucky were identified.

- Conservative estimates of the number of people with brain injuries suggest that 3,395 Kentuckians acquired a brain injury in 1997. Using information from the Centers for Disease Control and Prevention, it may be estimated that 2,935 people in the commonwealth received a traumatic brain injury in 1999. This estimate does not include people who may have received brain injuries as a result of anoxia, hypoxia, acute medical incidents, allergic reactions, or similar events.
- Additional mechanisms for collecting data about the incidence of acquired brain injuries are necessary to determine the full impact of this disabling condition on Kentuckians. Existing programs for persons with disabilities may not be required by their funding sources to report a diagnosis of brain injury, making it difficult to obtain accurate information about the prevalence of persons with brain injuries in those systems.
- People with brain injuries are seeking assistance from providers of services designed to meet the needs of individuals with a variety of disabilities. There is reason to be concerned about the number of people with brain injuries using mental health and substance abuse services. A high proportion (44%) of clients screened in randomly selected programs reported a history of one or more brain injuries.
- Survey data indicate that 44% of respondents acquired a brain injury prior to age 22 years. Because they were injured during the developmental period, these persons may be eligible for services from Mental Retardation/Developmental Disabilities programs, adding to the demands on that already overburdened system.
- Fewer than 1% of persons using Mental Retardation and Developmental Disabilities services operated by community mental health centers and 14% of the residents of

state-operated ICF's/MR were estimated to have brain injuries. Given the proportion of survey respondents injured prior to age 22 years, this finding is believed to reflect a need for more accurate data collection regarding the etiology of the disability, rather than an absence of any need to access these services.

- The need to provide information, training, and support to existing providers serving people with brain injuries is acknowledged.
- People with brain injuries may need life long services and supports. The needs for long term case management and access to information are recognized. Because of the limited number of case managers available to serve persons with acquired brain injuries, access to resources and appropriate care may be hindered.
- Responsibility for caring for people with brain injuries is most likely to rest with family members rather than with paid caregivers. Families report the need for additional supports to assist them in caring for their loved ones. These include respite care, financial counseling, legal counseling and financial assistance with medical expenses.
- Focus group participants emphasized a need for residential services. These groups identified the need for a full continuum of residential services ranging from a self-contained campus to less restrictive community placements. Survey respondents, however, overwhelmingly (94%) reported a preference to remain in their own homes in the future. The available data suggest that a small number of people with brain injuries may need residential placement outside their own homes.
- Many people with brain injuries are unemployed, but wish to be employed in some capacity. The need for meaningful day activities and programs was emphasized.
- The services most frequently indicated as needed by survey respondents and focus group participants were case management, psychological and mental health, cognitive rehabilitation, residential, and employment services. The need for support groups and assistance with transportation was highlighted.
- The need to further study the prevalence of substance abuse problems among persons with acquired brain injuries in Kentucky was noted.
- Only 24% of all survey respondents reported their needs were being met. The most frequently cited reason for this was the respondent's lack of knowledge about what would be helpful. The need for information about the effects of brain injuries and services available to help accommodate to those effects is emphasized.
- Although services for persons with disabilities are available throughout much of Kentucky, the unavailability of services in the respondent's area was the second most frequently given reason for needs being unmet. Reasons for unavailability are not clear and deserve further exploration.
- Two programs designed specifically for people with brain injuries are the Acquired Brain Injury Medicaid Waiver Program and the Traumatic Brain Injury Trust Fund. Because of restrictive eligibility criteria and limitations on funding, these programs are not anticipated to provide long-term supports at this time.
- The largest burden for payment of needed services and supports for persons with brain injuries clearly rests with Medicaid and Medicare, with 61% of survey respondents indicating a use of at least one of these resources.

- Publicly funded programs designed to serve people with a wide variety of disabilities are also available to individuals with brain injuries. These include but are not limited to Medicaid waiver programs, IMPACT and IMPACT Plus, mental health programs for children and adults, programs for persons with mental retardation and developmental disabilities, specialized health care programs, and programs offered by the Office of Aging Services and the Department of Vocational Rehabilitation. Barriers to accessing some of these services include lengthy waiting lists, restrictive eligibility criteria, and a need to ensure expertise in the field of brain injury.
- Other gaps in service include long-term residential care for adults with brain injuries, prevention efforts, and easy access to critical information.

## The Next Step: Strategies for Filling the Gaps in Services For People with Acquired Brain Injuries In Kentucky

### **Values**

One key to developing services is to identify the values that serve as the foundation for action. The Planning Project Advisory Group assisted in detailing these, which are listed below.

- People with brain injuries deserve respect and are valued members of their homes and communities.
- Services support, rather than supplant, the efforts of people with brain injuries, their families, and their loved ones to remain in their own homes and communities.
- People who use services direct their own care to the greatest extent possible.
- People with brain injuries have choices.
- Services enable people who use them to be as independent and productive as possible.
- Services are provided in the least restrictive environments.
- Services are accessible, available, and effective.

### **Strategies for the Refinement and Development of Services for People with Acquired Brain Injuries in Kentucky**

The following strategies for refining and developing services for people with brain injuries in Kentucky have been identified from the evidence in this report. This report will serve as the Action Plan for the Brain Injury Services Unit which will seek the cooperation and investment of key agencies and community members to implement these strategies.

1. Maximize the ability of people with Acquired Brain Injuries, their families and their loved ones to plan for and support themselves in their own homes and communities.

#### **Suggested Actions:**

- Improve patient education about the effects of acquired brain injuries and the services available to help cope with those effects
- Provide a centralized information and referral source for people seeking information about brain injury or services
- Facilitate workshops for families about financial planning
- Facilitate workshops for families about legal issues, specifically guardianship, advance directives, and the legal system

2. Maximize the use of existing programs and resources available to persons with disabilities.

Suggested Actions:

- Increase the number of case managers statewide who have expertise in the field of acquired brain injury
- Educate case managers about services available to people with disabilities, including brain injuries
- Provide a resource guide to case managers, advocates, and potential referral sources
- Work to identify and amend regulations that may prevent or inhibit access to programs by people who have brain injuries
- Promote participation of people with brain injuries in the advocacy efforts of other groups supporting persons with disabilities

3. Partner with existing programs and providers to increase their capacity and expertise to meet the needs of people with brain injuries.

Suggested Actions:

- Facilitate the provision of easily accessible consultation to providers who are now serving people with brain injuries. Develop a cadre of consultants or program specialists who can assist providers in working with specific individuals.
- Identify and support the efforts of programs serving people with disabilities to become more accessible to persons with brain injuries
- Advocate for required training about brain injuries for professionals and for staff of publicly funded programs serving people with disabilities. Assist in the development and provision of such training.

4. Focus on the prevention of brain injuries

Suggested Actions:

- Partner with and support existing prevention programs like Mothers Against Drunk Driving, Kentucky Injury Prevention and Research Center, Safe Kids Coalition, and the Brain Injury Association of Kentucky
- Seek funding for prevention activities
- Seek legislation that may help reduce the incidence of brain injuries in Kentucky
- Focus on the prevention of brain injuries among teenagers

5. Divert existing funds to allow for provision of needed services

Suggested Actions:

- Increase the number of case managers statewide who have expertise in the field of acquired brain injury
- Increase the availability of long-term community residential services for adults with brain injuries.
- Create a continuum of care that is sensitive to the needs of some individuals with brain injuries to move between programs of varying levels of restrictiveness

6. Plan for the future

Suggested Actions:

- Further assess the availability of in-home supports for people with brain injuries and their families, and the long-term availability of those supports, especially respite care.
- Improve the mechanisms for collecting data about the prevalence of persons with brain injuries who use existing publicly funded programs
- Determine when the greatest number of people with elderly caregivers are likely to need publicly funded services
- Determine the number of children with brain injuries currently receiving services who will continue to need publicly funded services as adults
- Improve data collection about the incidence and prevalence of brain injuries in Kentucky
- Educate legislators about the needs of people with brain injuries and their family members

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